

International Handbook of Human Response to Trauma

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Kluwer Academic / Plenum Publishers
New York, Boston, Dordrecht, London, Moscow

Obstacles to Assessment of PTSD in Longitudinal Research

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Despite the burgeoning literature on the assessment, diagnosis, and treatment of post-traumatic stress disorder, there are few empirical findings to guide clinicians and researchers in anticipating how individuals with PTSD will fare over a time span of years. This chapter first briefly overviews current findings about the course of PTSD and then identifies reasons why longitudinal investigations of PTSD have been largely bypassed by PTSD researchers.

What We Know about the Course of PTSD

Great strides have been made in recent years in developing psychometrically sound instruments to identify PTSD and assess its severity (see Newman et al., 1996, for a review of measures). This sophistication in measuring PTSD has allowed researchers to examine PTSD symptoms in both retrospective and prospective studies. Retrospective investigations have documented that PTSD symptoms can persist for decades following a traumatic event (Green et al., 1992; Kulka et al., 1990). For example, the National Vietnam Veteran's Readjustment Study (NVVRS; Kulka et al., 1990), the largest, most comprehensive study of combat-related PTSD to date, found that 15% of the veterans evaluated had current symptoms of PTSD. An additional 15% of the participants in this study reported that they met criteria for lifetime PTSD (i.e., they had previously experienced such symptoms but did not at the time of assessment).

Several researchers have examined PTSD symptoms prospectively over months following extreme stressors such as rape (Rothbaum et al., 1992), assault (Riggs et al., 1995), motor vehicle accident (Frommberger et al., 1996; Klein et al., 1996), and a bush-fire disaster (McFarlane, 1988, 1989, 1992). These studies suggest that, for the majority of individuals, PTSD symptoms are present immediately following a potentially traumatic event.

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International Handbook of Human Response to Trauma, edited by Shalev, Yehuda, and McFarlane. Kluwer Academic / Plenum Publishers, New York, 2000.

matic event, recede over the subsequent months, and eventually remit after several months. However, for a substantial minority of people, the symptoms persist.

Other research has indicated that PTSD symptoms can be reactivated after periods of relative dormancy. Life stressors, such as retirement, death of a parent, or children leaving home, have precipitated PTSD symptoms in World War II combat veterans (Christenson et al., 1981). Visits to war memorials and other public ceremonies that were reminders of combat have been reported to exacerbate symptomatology in Vietnam veterans (Faltas et al., 1986). Solomon (1993) documented how the 1982 Lebanon War reactivated symptoms in Israeli combat veterans of the 1973 Yom Kippur War.

In a prospective study of veterans' health service utilization, Ronis et al. (1996) found that the use of mental health services by PTSD patients was both persistent and episodic. The investigators concluded that the absence of PTSD symptoms does not mean that the disorder has resolved for these patients.

Thus, research is accumulating which suggests that

- PTSD symptoms develop acutely in many individuals following an extremely stressful or potentially traumatic event;
- PTSD persists and becomes a chronic disorder in a substantial minority of these individuals; and
- symptoms are frequently reactivated after periods of dormancy.

Many questions remain unanswered, however. It is clear that there is considerable individual variability in the chronicity and course of PTSD although the factors that contribute to this variability are largely unknown. Prospective, longitudinal research is needed to inform us when and how the disorder recurs and fluctuates.

Why We Do Not Know More

Although vital to our knowledge about the course of PTSD, longitudinal research in this area is scarce. We will use our follow-up study of Vietnam veterans with PTSD as an illustration of some of the obstacles that have limited research in this area.

Recruitment and Retention Difficulties

Longitudinal or follow-up research on any population is arduous, time-consuming, and expensive. Researchers have bemoaned the low rates of subject retention in longitudinal investigations (e.g., Capaldi & Patterson, 1987). Suggested methods for maintaining contact with study participants and maximizing subject participation (e.g., Twitchell et al., 1992) require extensive resources. As a result, longitudinal studies with high rates of retention are rare.

There is also evidence suggesting that individuals with PTSD may be even more difficult to recruit and maintain in such studies than other populations. Sparr et al. (1993) demonstrated that clients with PTSD and/or substance abuse are more likely to miss psychiatric appointments than clients with other disorders. Niles et al. (1997) found that patients in a primary care clinic who endorsed symptoms of PTSD on a self-report screening form were more than twice as likely to refuse or be unavailable for follow-up telephone interviews than patients who did not endorse PTSD symptoms.

The avoidance symptoms that are elements of the diagnostic criteria for PTSD may contribute to this low rate of follow-up. Because a person with PTSD "commonly makes deliberate efforts to avoid thoughts, feelings, or conversations about the traumatic event (Criterion C1) and to avoid activities, situations, or people who arouse recollections of it (Criterion C2)," (American Psychiatric Press, 1994, pp. 424-425), it follows that such an individual would seek to avoid researchers who attempt to ask questions about the event or probe into reactions to it. A general distrust of authority is a characteristic that is also commonly associated with the disorder (Blake et al., 1990). In the case of combat veterans, who are often skeptical and distrusting of anyone who represents the government, recruitment calls or letters from government researchers may be met with hostility or extreme avoidance.

Problems of homelessness or transience are also common in chronic PTSD cases. For example, in a recent evaluation of U.S. Veterans Administration inpatient treatment for Vietnam veterans with PTSD, 33% of the sample was homeless or living in a hospital (Johnson et al., 1996). These problems further complicate the difficulties of finding and following clients in longitudinal research.

In the study we conducted, all of these factors appeared to contribute to difficulty in follow-up. This study was conducted to examine the course of PTSD symptomatology in veterans who had been evaluated in the Boston Veterans Administration PTSD clinic in the late 1980s (Time One). In 1994 and 1995 (Time Two), the research team attempted to locate, contact, and recruit all 111 Vietnam veterans who had been evaluated for combat-related PTSD at Time One. Thirty-eight (34.3%) completed the follow-up protocol, whereas 19 (17.1%) declined to participate, 14 (12.6%) were identified as deceased, 16 (14.4%) were reached but failed to appear for the evaluation, and 24 (21.6%) could not be located despite extensive efforts, including the use of a national locator service.

One unanticipated factor that limited the number of participants at Time Two was the high number of deaths in this group. The rate of death over the average 6.6 years between Time One and Time Two was more than five times the national average for men of comparable age in the United States (U.S. Bureau of Census, 1994). Thus, one sad finding from this study is that premature death in this population also limits follow-up of the course of symptomatology.

Because follow-up rates are low in this population, another issue to consider is that those individuals who do participate in follow-up studies may not be representative of the entire group. Our follow-up study provided some evidence of this: those who participated at Time Two were shown to have significantly lower (i.e., less impaired) Time One scores on a variety of PTSD and related psychopathology measures than either those who died or those who did not participate. One potential remedy for this would be to use a prospective design, where individuals are approached at the outset of their initial assessment and are asked to participate in a longitudinal evaluation. Such an approach would be likely to boost rates of follow-up participation, but prospective studies can also have high rates of refusal. Therefore, there are important limitations on how much one can generalize the results from follow-up or prospectively designed longitudinal studies of individuals with chronic PTSD.

Overall, it is very difficult to locate and complete evaluations of individuals with PTSD in follow-up studies. Once individuals are successfully located and persuaded to participate, the next obstacle is measurement of changes.

Measurement Difficulties

Current demands on health care providers to demonstrate effective treatment has led to recent emphasis on psychometric instruments designed to demarcate improvements in mental health patients. However, the symptomatology accompanying PTSD is extremely complex, and it is difficult to identify or target specific symptoms with which to measure change. Determining what, how, and when to measure has been a great challenge in research on PTSD (e.g., Bleich et al., 1992; Shalev, 1997).

What to Measure

Aggregated Data and Individual Variability. Examining differences over time in mean scores on psychometric measures appears to be a useful way to investigate changes for a group. However, using only group means to characterize changes for a number of individuals with PTSD may lead one to draw spurious conclusions about the individuals. For example, Table 1 depicts the mean Mississippi Scale score for the group and the individual scores for the veterans who took part in the Time Two evaluation in our follow-up study of combat veterans. The difference in mean scores between Time One and Time Two indicated very little change over time. At both Time One and Time Two, the mean score was well above the suggested 107 cutoff indicating PTSD for combat veterans (Keane et al., 1988). However, when the individual scores were examined, it

TABLE 1. Comparison of Time One and Time Two Mississippi Scores for Group and Individuals

	Mississippi Scores				Mississippi Scores		
	Time One	Time Two	Difference		Time One	Time Two	Difference
Group mean	123.37	120.91	-2.20	Individual	150	152	2
Individual	142	85	-57	scores	134	139	5
scores	127	89	-38	(cont.)	136	143	7
	126	93	-33		106	116	10
	89	57	-32		142	153	11
	134	104	-30		94	105	11
	145	117	-28		140	154	14
	160	132	-28		107	123	16
	97	73	-24		94	113	19
	125	107	-18		120	142	22
	130	112	-18		130	152	22
	132	116	-16		111	134	23
	93	79	-14		100	126	26
	160	146	-14		122	154	32
	92	79	-13		115	151	36
	128	116	-12		99	156	57
	132	123	-9		144	-	-
	145	140	-5		90	-	-
	126	125	-1		145	-	-
	126	126	0				

became apparent that there were dramatic changes in some cases: a few individuals moved three standard deviations up or down in symptomatology, as measured by this scale. Therefore, examination of group means can obscure dramatic individual changes.

Domains and Symptoms. It seems obvious that measuring of the specific symptoms of PTSD would be the central domain for research on the course of PTSD. One might assume that a focus on the diagnosis of PTSD would be useful in examining its course over time. However, whether an individual's symptoms are sufficient to meet diagnostic criteria is often not a meaningful distinction in chronic PTSD. In severe cases a PTSD diagnosis may be maintained even when symptoms abate substantially. In less severe cases an individual's symptom levels may hover around diagnostic cutoffs, falling below at one point and above at another. In this situation, use of a dichotomous diagnosis variable to represent PTSD can allow minor fluctuations in symptoms to appear greater than they really are.

Measuring the number and severity of PTSD symptoms and how they fluctuate over time might allow for a more sensitive examination of changes. However, even when the units of measurement are quite refined, PTSD symptoms for a group may not change substantially in the chronic phase of this disorder (Johnson, 1997; Shalev, 1997). Comorbid psychopathology, related symptomatology, and quality of life assessment may provide better information about change. Comorbid disorders, especially depression and substance abuse, are pervasive in the veteran PTSD population (Keane & Kaloupek, 1997; Keane & Wolfe, 1990; Sierles et al., 1983) and should be assessed to illustrate a full picture of symptomatology.

Therefore, it is unclear whether the large changes in Mississippi Scale scores shown in Table 1 represent meaningful changes. Close examination of some of these cases has demonstrated that the Mississippi Scale taps PTSD symptoms only and is not a good indicator of overall functioning. For some individuals, great strides may be made in other areas of functioning even when PTSD symptomatology increases. (See Niles et al., 1998 for a case study illustration of this phenomenon.) It is a great challenge to determine the relative importance of various symptoms when individuals present uneven patterns of strengths and difficulties.

Criterion A Events. When individuals have experienced many potentially traumatic events, it can be difficult to decide which or how many of them contribute to the post-trauma symptomatology. There are several reasons that there may be shifts over time in the way various events affect current functioning. For example, in the case of combat-related PTSD, war-zone experiences are considered the "index events" that are identified as Criterion A for the diagnosis. Many soldiers suffered several traumatic experiences while in the war zone, and the relative significance of these events may change over time for the individual. Also, many veterans experienced nonmilitary traumatic events both before and after their military traumas. In some cases, these additional events may be more distressing for the individual than the identified index event. In longitudinal research, an individual might experience a new traumatic event subsequent to the beginning of the research project. A dramatic increase in PTSD symptomatology may result from such an experience. Finally, subjective appraisal of a specific event may change. Several recent studies have documented that estimation of combat exposure, for example, can change dramatically over time (Niles et al., 1999; Roemer et al., 1998; Southwick et al., 1997). Therefore, when examining the course of

PTSD in longitudinal research, it is important to consider that the differential salience of traumatic events may change over time.

How To Measure

Assessment of symptoms can also be challenging. The most common method of gathering information about psychiatric symptomatology is to ask the individuals to rate their symptoms. Several valid and reliable self-report checklists have been developed to assess PTSD symptoms, and some assess related symptomatology as well. For example, as mentioned before, in our follow-up study the 35-item Mississippi Scale for combat-related PTSD (Keane et al., 1988) was used to assess PTSD symptoms. This scale has been widely used in assessing combat-related PTSD and has performed well as a self-report measure of the disorder (Kulka et al., 1990).

The advantage of self-report assessment measures is that they are cost-efficient and do not require clinician time for administration. In addition, the ratings are not influenced by potential clinician bias. However, an important shortcoming of such instruments is that they have a limited ability to indicate whether the information provided is accurate. Individuals may exaggerate or underestimate on ratings, misunderstand the questions, respond randomly on the questionnaire, and/or be poor observers of their symptoms.

Clinician-administered structured or semistructured interviews have also been widely used for assessment. Two commonly used instruments of this type, the Structured Clinical Interview for DSM-III-R diagnosis (Spitzer et al., 1990) and the Clinician-Administered PTSD Scale (Blake et al., 1990), were used in our follow-up study. In such an interview, a clinician can ensure that all symptomatology is reviewed in detail while allowing interviewees to describe their symptoms in their own words (Newman et al., 1996). The clinician can use both verbal and nonverbal information to evaluate whether the interviewee understands the questions or is responding randomly and can guide the interview accordingly. In addition, a skilled clinician can often detect when an interviewee is overstating or understating symptoms. However, clinician judgment can also be biased or inaccurate. Unfortunately, both self-report and clinician-administered PTSD assessment instruments do not have psychometrically valid and reliable ways to determine the individual's reporting style.

Psychophysiological assessment of PTSD, that is, measurement of physiological reactivity to exposure to cues of the traumatic event, can offer important additional information in a comprehensive assessment. Measures of heart rate, blood pressure, muscle tension, and skin conductance do not rely on either self-report or clinician judgment. This minimizes the impact of response sets or biases. However, psychophysiological reactivity is considered an indicator of PTSD, not a definitive measure. These assessments have good specificity, but the sensitivity is low (Gerardi et al., 1989); reactivity can be influenced by many outside factors, such as psychotropic and antihypertensive medications (Prins et al., 1995). In addition, in many outpatient settings, the resources necessary for such assessments are not available.

Reports from partners, family members, or friends can also provide valuable information in clinical assessment. Collateral assessment of PTSD can bypass some of the obstacles to accurate self-reporting, such as denial, reading comprehension problems, avoidance, or amnesia. However, collateral information is often not accessible to the assessor. When it is, it is also subject to influence from biases and response sets.

All of the measures described above can provide meaningful information in an assessment but are associated with some degree of error. The literature on the evaluation of PTSD has greatly emphasized the importance of combining data derived from self-report interviews, structured clinical interviews, and, when possible, psychophysiological assessment and collateral reports (e.g., Keane & Kaloupek, 1997; Keane et al., 1987, 1996; Kulka et al., 1990). When comprehensive multimodal assessment is used, the strengths of some measures can compensate for shortcomings of others.

When To Measure

A limited number of empirical studies and some clinical illustrations have demonstrated that chronic PTSD is both persistent and fluctuating. The striking persistence of PTSD symptoms has been widely discussed in clinical literature, particularly with regard to combat veterans, in descriptive accounts (e.g., Horowitz, 1986, 1993) and in the emerging treatment outcome literature (e.g., Johnson, 1997; Shalev et al., 1996). In the NVVRS (Kulka et al., 1990), about half of the Vietnam veterans who reported that they ever met diagnostic criteria for PTSD were also diagnosed with this disorder when they were assessed in the late 1980s. The remarkable chronicity and severity of PTSD in Vietnam veterans who seek inpatient VA PTSD treatment has led Shalev (1997) to suggest that long-standing combat-related PTSD in Vietnam veterans may be "treatment-resistant" in many cases. In all, these findings support the conceptualization of PTSD as a chronic, unremitting disorder.

Yet there is also compelling evidence for fluctuation in the symptoms of PTSD. The other half of the veterans in the NVVRS, who were diagnosed as having had PTSD in their lifetimes, reported that their symptoms had decreased to such an extent that full diagnostic criteria for PTSD were no longer met (Kulka et al., 1990). This suggests that at least some symptoms remit over time.

Because there is considerable variability in PTSD symptomatology over time and individual scores on various measures may go up and down considerably, group means may not change substantially. General trends for a group are hard to detect when data are aggregated and when there is a large dispersion of changed scores for individuals. Figure 1 represents some possible scenarios. It illustrates how improvements for a group might not be detected when only two times are examined. Individuals

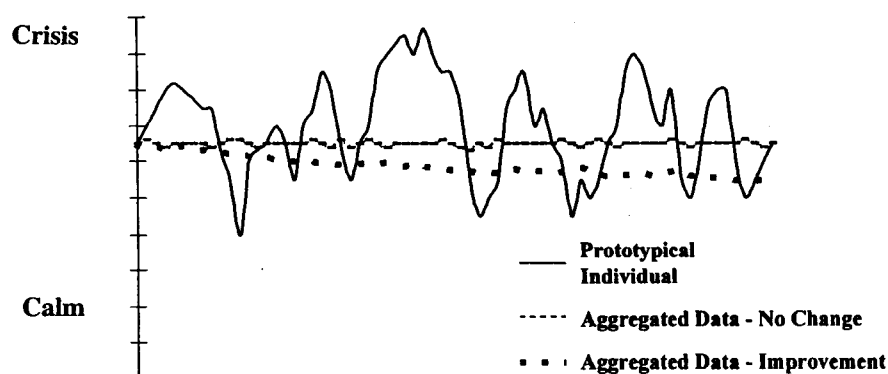


FIGURE 1. Hypothesized fluctuation of symptoms in chronic PTSD.

may fluctuate up and down, but when data are collapsed or averaged, the line appears relatively flat. Subtle but real changes for the group may be overlooked.

Conclusions

Multimodal assessment, including both observed and subjective reports of improvement or change, is recommended in examining the course of PTSD over time. However, numerous assessment measures can be labor-intensive for both the individuals under study and the investigators: this may limit compliance with follow-up. Nevertheless, it is important to develop a representative picture of individuals who have chronic PTSD so that changes in functioning can be accurately portrayed. In addition, multiple points of measurement in longitudinal research are also needed so that subtle trends can be detected.

A great deal remains unknown about the course of chronic PTSD. Although longitudinal investigations in this area are extremely challenging, this line of research is crucial. Greater understanding of the PTSD symptom course and the impact of variables such as life stressors or social support will provide a necessary base for the systematic development of interventions to control and reduce chronic PTSD.

Acknowledgments

We want to express our appreciation for the contributions of Danny G. Kaloupek and Terence M. Keane, who provided the Time One data set and financial, scientific, and editorial support for this project. We also thank Melissa S. Covington for her help in the preparation of this manuscript.

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